

# Care.data: democracy and health experts respond to concerns over the privacy of NHS patient information

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By Democratic Audit UK

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*The planned NHS scheme in which patient's medical records would be compiled into a national database for research purposes has been [postponed](#), amid concerns that the project was communicated poorly to the public. In this post, we ask democracy and health experts to share the views on the value of the care.data scheme and the important safeguards around the privacy of personal information that need to be in place before any re-launch.*

## **Sharmila Nebhrajani, Chief Executive of the [Association of Medical Research Charities \(AMRC\)](#)**

*Care.data is a good idea currently stymied by poor design, poor execution and dreadful communications. Medical research charities understand very well how patients' involvement in research is a gift that cannot be taken for granted. 80% of people told us in 2011 that they would offer their data for medical research. Given that this is some of our most personal data it is an extraordinary, altruistic act. It is a gift just as precious as blood or a kidney.*



*Here are some of the things that must be solved before the public can feel comfortable in making that gift:*

- There must be greater awareness, clarity and information out there for people to make an informed decision. An opt out is a legitimate approach – to avoid bias and gain the value of scale -but should not be used as a way of hoodwinking the population or relying on their inaction.*
- It must be clear who might have access to that data and crucially who would not. Access for researchers in pharma and biotech with legitimate research questions might be acceptable whereas companies seeking to use it in marketing or insurance would not be.*
- We need to know if the data will also be available to government departments, the DWP or HMRC for example, who may really have no role in medical research or healthcare provision.*
- The safeguards and penalties for misuse must be clearly laid out.*
- And finally, the opt out should be made as simple as possible with a form distributed to all.*

*This pause (in fact the second) needs to be used constructively to fix these problems, and quickly – before the public lose confidence in this important project.*

**Dr Ela Klecun, Assistant Professor of Information Systems, LSE & Dr Simon Taylor, Reader in Computing, Brunel University**

*Privacy and implementation – the care.data debate continues. What about the individual citizen? What about NHS accountability? Currently, the NHS publishes data on patient experience, aspects of patient safety and patient outcomes. Care.data will hugely increase the amount of data available for analysis. Will members of the public be able to analyse the (anonymised aggregate) data and build their own models? Will we see the rise of the citizen analyst? This is both inspiring and worrying.*



*People being able to use data to present complex arguments – what's wrong with that? There is a danger that models built will be incorrect, based on wrong assumptions and that too much reliance will be placed on contextual data. How can we help to reduce this danger? People will need tools for data analysis and information on how to use them and how to interpret the results. Yes, pressure groups might use such data to champion their specific causes to the detriment of those less vocal but there is also much scope for learning and engagement. Care.data, and more generally Big Data, should strengthen the public's ability to call decision makers to account.*

**Eddie Copeland, Head of Digital Government Unit, Policy Exchange**

*Despite care.data's shortcomings, the principle of using data to improve public services is not only sound but essential. Data analytics can help the NHS be more responsive to patients and also more cost effective. To succeed, patient support is vital. We need a clear articulation of the benefits of the scheme; how our data will be anonymised, used and shared; and a simple mechanism for opting out.*



*Longer-term, health data initiatives must focus on the patient. Citizens should have access to their own electronic healthcare records and be able to assign access rights to the medical professionals of their choosing. Incentives could be offered for patients to share their data for research, for example having the ability to compare their own health information with aggregated records of those of the same demographic or medical condition. This model would reward patients, build trust on how their information was used, and ensure a proper mechanism for giving consent.*

**Emma Carr, Deputy Director, Big Brother Watch**

*The care.data scheme has laudable aims. However, the structure and implementation of care.data has been woefully communicated and unnecessarily rushed, undermining trust in patient confidentiality and the wider role of data in the NHS. If trust is undermined the NHS is fundamentally weaker and patient care will suffer.*



*The lack of clarity over what data would be extracted alongside conflation of various uses of data within care.data – from drug research to the monitoring of performance and*

*treatment successes – meant that the public had understandable concerns about the scheme.*

*From an ethical and privacy perspective, an opt-in system should be the norm, not the exception. It is contradictory to aspire to allow patients to control their own records, only to then pursue an opt-out system.*

*The amendments that have been put forward to the Care Bill address some concerns, however there are still questions that must be answered – for example, will any data flow if a patient opt-outs – before the public will have full confidence in the scheme.*

***Dawn Monaghan, Group Manager, Public Services at the [Information Commissioner's Office](#)***

*Our focus has been around how much patients know about the planned changes. The Data Protection Act requires GPs to inform patients, though NHS England is taking the lead in helping GPs to do this.*



*The communications strategy NHS England showed us looked likely to meet the legal requirements, but the implementation has fallen short. Specifically, we don't feel the opt out has been explained as clearly as we expected. It's up to the Health Secretary to decide how the opt out should work, but people need to know what their options are.*

*The postponed start date should give NHS England a chance to address this. We can't dictate how they should tell patients about the changes, but we can be clear what their legal obligations are. We'll wait to see their response with interest.*

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